Deaf-Accessibility for Spoonies: Lessons From Touring *Eve and Mary Are Having Coffee* While Chronically Ill
For RiDE (Research in Drama Education)

Khairani Barokka (Okka)
Writer . Poet . Artist
PhD Researcher, Goldsmiths Visual Cultures
http://khairanibarokka.com
kbarokka@gmail.com / kbaro001@gold.ac.uk

3,479 words

Abstract:

This essay, as a provocation from the field, presents lessons learned from mishaps and off-the-cuff solutions to touring a deaf-accessible show with limited physical resources, illuminating how pain and suffering can hide in plain sight, on a global stage, in the hopes that it may be prevented. In 2014, I toured solo deaf-accessible spoken-word/performance art show *Eve and Mary Are Having Coffee* (itself addressing ableism and misogyny, and drawing attention to invisible disabilities) in various forms in the UK, Austria and India, with a grant from HIVOS. As an Indonesian woman who was and am living with extreme chronic pain and fatigue, this essay will present lessons learned from the harsh difficulties and successes inherent in making a show accessible to one disability culture, whilst struggling with one's own. Examined herein will be intersections of accessibility to pained women, to deaf women, and the framing of disabled women from non-Western backgrounds performing in various contexts—querying and entangling assumptions as well as expanding on the literature around performance and chronic pain in terms of Eve's intentions and manifestations. This article will also include media in the form of photography and video from the tour.

Keywords: Poetry Performance, Performance Art, Disability, Intersectionality

—

Pain hides in plain sight. This assumption, that what another feels they perceive confirms absolutely: *you are not in pain*, is not unfamiliar to anyone who lives with chronic pain, lives the exact opposite truth. Yet the shock of distance, of misunderstandings from human beings so close to our bodies, to the truth as we inhabit it in our bodies, can be something else entirely. What I

realise now, two and a half years after writing, performing, and producing solo poetry-art show *Eve and Mary Are Having Coffee*, is that I would be reminded of this extreme gulf, between perception of my pain by self and by others, in assaulting, traumatic ways, over and over again. In London, Edinburgh, Vienna, and New Delhi. In a small theatre at the Fringe, in a window seat stage in a former Vienna red-light district, in a community arts centre, and in a New Delhi amphitheatre. This was my experience of the year 2014.

Perversely, the absolute facts of miscomprehension, the inability to transfer someone into our bodies to experience what we feel, were at the root of both the extreme chronic pain I've experienced for five and a half years now and the impetus to create a show that would illuminate this pain where people saw none. To realise a form of interpretation that was not only ocular-centric —as I would paint my right side and chest in the blue "coffee" that a pantheistic deity had poured over my nerves, and provide the script in full on devices for hearing-impaired audience members— but audiocentric, as poetry equal parts ominous and whimsical described abstractly the bizarre, frustrating, hopeful and livid states of living with this condition as an artist, as a woman, as an Indonesian woman abroad, living with what I perceive as intergenerational trauma in my body, as well that induced by healthcare abuse and neglect.

As I imagine is the case for most people, the sheer impossibility of human communication is why we attempt to bridge it anyway, by writing, speaking, creating, by touch, by existing in groups, by sustaining ourselves for the attempt to bridge gaps. Perhaps it is only right, then, that my years of research as an independent scholar-practitioner in arts and writing, and now in Goldsmiths' Visual Cultures PhD program, focus on the topics of pain, visuality, art, and the empathy gap. My experiences in 2014 with *Eve and Mary Are Having Coffee* continue to feel vital in this process.

In telling this story, it might serve you, the reader, to know that in late 2015, I came to my GP in London, and told her the painkillers she'd prescribed for me had not been working. I still found myself in tears while doing the laundry, unable to cope with the sting in my nerves. Upon arriving to London, I'd registered with her practice, asked for help with pain, and had been given a certain dosage of Gabapentin, a benign form of painkiller as far as they go.

Now, however, her face changed. She may have asked me a few more questions. The doctor then asked me why I hadn't been in a pain and rehabilitation clinic from 2011, when my body first began to feel as though it was covered in knives, from the back of my ear to my shin, causing my body to then buck uncontrollably, and my right eyelid and the right side of my lips unable to open. The severe, constant sting bubbled over the entire right side of my body, and was especially insidious in my chest. Over time, with piecemeal acupuncture and failed attempts at rest, my body regained the ability to walk, but in late 2015 my chest in particular would still assault me after two to three hours of sitting up. It is still the case today, though that length of time is very slowly increasing.

To make a long story short, the help I'd needed wasn' there. Having been repeatedly mistreated by the medical system in New York City, where the pain crisis had first flared up after obtaining my masters, my family in Indonesia took me to an MD-acupuncturist who'd helped, but not nearly to the extent I needed. Pain was hidden well, and I began to attempt to work in the arts and disability sector. Having always written, I began in 2012 to perform and produce spoken word shows, which took me to Australia, Malaysia, Singapore, India, around my own Indonesia, and, with the benefit of knowing how to write, produce, and perform a one-hour, one-woman show standing up--to much pain after, and sometimes during, the production--I decided to embrace and protect my disability in 2014, by creating a show entitled *Eve and Mary Are Having Coffee*. I take here the social model notion of disabled as the opposite of "enabled" rather than "unable", a perspective that I think is particularly useful psychologically, for myself and I imagine other young, brown, disabled women, told in so many ways that we are not valuable, beautiful, equal. The show Eve and Mary Are Having Coffee touches on these intersectional issues, and in it, I am 98% of the time kneeling or laying down, performing poetry and performance art whilst refusing to stand and cause myself pain, whether seen by others or not.

My GP in London didn't hear much of all the details I've just told you, but to her immense credit, she saw through my skin and understood the extent of the nerve damage. She then prescribed me the highest possible dosage of Gabapentin, 10 times the original prescription, which continues to work in conjunction with self-management of energy and pain. It's been trial and error

as always, but for the most part, it feels like sheer relief compared to before this medicine entered my body. I am set to begin a holistic pain management program next year, sponsored by the NHS, and have seen pain specialists within the medical system here. I've been assigned an occupational therapist. Finally, I feel my pain is truly understood.

However, in 2014, I was reeling from (quite literally) working under other people's assumptions that my pain was negligible, lack of proper healthcare, and setting unduly high expectations for the arts work I'd become immersed in. I'd decided to do *Eve and Mary Are Having Coffee* as a poetry/art show that both spoke about the pain and allowed the pain to be visual--throughout the show, I pour and rub in blue "divine coffee" paint all over the right side of my body and chest. I wanted to make an "invisible disability" visible, through refusing to stand up to perform, and through the paint's visualisation of my pain. I would tour *Eve and Mary* first in London, with a preview show at a community arts centre, in conjunction with a workshop for disabled women of colour. It was then on to an abbreviated preview at the University of Warwick at the International Federation for Theatre Research conference, where I was (and remain) a member of the Performance and Disability Working Group. Then on to Edinburgh Festival Fringe, where I found myself the only Indonesian delegate, for a week-long run; to Vienna, where I performed at Mz Baltazar's Laboratory, a feminist hackerspace; to New Delhi, where I performed a segment of *Eve and Mary Are Having Coffee* at an international arts and disability conference, which meant I performed a Phil Collins joke stanza just before a speech by the Indian Supreme Court Justice in attendance (great timing).

I made sure I'd enforced rules on *Eve and Mary Are Having Coffee*: it would be D/deaf and hearing-impaired accessible, and only performed in wheelchair-accessible venues. The script was put on a Google Document, and the shortened link given to D/deaf and hearing-impaired audience members, who were asked to identify themselves beforehand, and were given iPads or iPhones with which to read the poetry. In Vienna, the link address was projected onto a wall, which meant anyone who saw it inside the gallery--or indeed outside it, as I performed in a window space facing onto the street--could read the script.

By the time I'd gone to the University of Warwick, however, I was already traumatised by the amount of pain it took for me to have put the whole thing together. This included the insensitivity of an arts organisation that later apologised to me for mishandling my request for support, holding several meetings asking me for further information that were physically difficult to attend, and failing to forward this information on (I later secured funding from another organisation, HIVOS, having obtained travel costs to and from Jakarta and Warwick University from an IFTR Bursary). At that point, in 2014, I'd lived three years with intense pain that few people truly saw; like many with chronic illness, pain and/or fatigue, we are said to "hide it well". I was already traumatised from the pain incurred after a successful solo travelling show, and so, feeling triumphant, exhausted, and deeply stressed by my physical experiences, when it came time to present my academic paper "Flightpath to Inclusion" at IFTR, I soon found myself reduced to tears before reaching the end of my exposition.

I remember a deeply empathetic group of academics and artists being kind enough to listen, and Petra Kuppers asking me what I do for self-care. It was so deeply embarrassing to have burst into tears, but at the same time, I wanted people to know: academia and the arts, for some of us, are contact sports. What we do literally bruises us, maims us, and brings to bear how our intellectual and artistic curiosity, our intelligence and our knowhow face head-on the fact of not being the recipient of proper healthcare for years.

All of my efforts, being from a country where pain management is near non-existent (even with the privileges afforded me as a middle-class Indonesian, whose family is very well-intentioned and has grown increasingly understanding of disability, though here too the communication gaps were difficult) and living in countries where my brown skin and gender discriminated against my receiving care, despite being on scholarships and receiving student health insurance, faced the simple fact: I had been given so profoundly much less than I needed in the way of proper medicine. Every bit of academic and arts work I had done had been done whilst withstanding what I would only in 2015 discover (with the GP's presciption) was truly an extreme amount of pain. It was a pain that is still having to be managed with the highest possible human dosage of an effective painkiller. A painkiller that in 2014, while creating and performing the show, I hadn't met yet, had

not been given or suggested to yet, because women's pain in particular, and brown women's pain (in Western settings in particular, but also found globally) is underestimated and undertreated.

Perhaps I wanted to be a "model minority". I was the only Indonesian artist at the Edinburgh Festival Fringe that year, let alone the only Indonesian, disabled woman artist; I may have been the first solo act from my country to ever attend. I would not go home, or go back; I would feel pain on my own, because of the joys inherent in performing, creating, communing with an audience, feeling less alone. Ironically, in order to produce, write, and perform a show about the vagaries of pain, the invisibility of pain, disabled identity and realities, the persistence of pain--and of multilayered pain, exacerbated by social conditions, what Yasmin Gunaratnam calls "total pain"—I'd paid such attention to how accessible the show would be for *other* disabled people who might want to see it, and because there had not been the option of dedicated care given to me, I'd given up on my body being allowed to be free of pain. Was just hopeful that the neurological chaos wouldn't be too overwhelming in the course of the tour.

This is a local but also transnational issue--we don't have federal funding for arts and disability in Indonesia. I knew that in order to put on the Fringe show, I'd have to seek funding independently. Being an independent artist, I couldn't afford to bring anyone else with me but myself. This is also a perspective that should contribute to the current conversations surrounding intersectionality in the academic world. In not making sure I'd be as painless as possible during the tour, as I did not have the required medicine nor body management knowhow (apart from what little I'd gathered in the course of three years), I'd actually denied myself the truth of the pain involved in a show about making pain apparent, as I was on an international stage, as small as I believe my endeavour was compared to some other productions. I was a representative of a country, a gender, and our minority community of disabled people--disabled people being, however, the largest minority in the world--and psychologically, there was the need to negate very real pain despite inadequacy of resources and operating solo.

Further, there were psychological blows to dignity, as in the case of the India conference, I was presented to a government official by conference staff thusly: "She can only sit up a few hours a day", before being given a scarf as an act of charity from the Indonesian government. My

colleagues suffered the same indignities, seen not as artists, scholars, nor even people capable of describing ourselves, but objects for charitable gifts. That same night, as I laid down in the darkened aisle awaiting my turn to perform, a volunteer asked me to “move back—this aisle is for the VIPs, and they can see you”. At a conference on arts and disability, where I was dressed for performance and about to go on stage to be seen and heard, as an audience member my presence was deemed offensive to VIPs.

As a teacher of performance and literature myself, learning from hindsight, I’d propose an intersectional, disability-aware exercise for production classes. I would ask them how, if they lived with chronic pain, they could continue to perform and produce whilst placing an undisputed premium on holistic self-care in complex circumstances, whilst maintaining an artistic practice.

In reflecting upon this particular arts adventure and my missteps (though truly, there seemed no other way to produce the show without inevitably inflicting harm upon myself), they seem reflective of a need for greater sensitivity towards intersectional understandings as needed in all arts productions:

a. In the sense of understanding and catering for audience members, artists, producers, and all others involved who are disabled, including those who are disabled in more than one way, within the framework of making a production accessible. This includes those who live with chronic pain;

b. The need for a greater acknowledgment of mental health issues in particular in the course of production, and for a full spectrum perspective on how deeply mental health issues are associated with lack of avenues to success in the arts for disabled practitioners;

c. Understanding that lack of treatment and recognition of pain’s severity, particularly among brown women in Western countries, and for women in countries whose healthcare systems are inadequate, breed terrible suffering, not least in the form of being used to not being understood as suffering. This, in turn, leads to the inability to seek out healthcare or help, as it was in my case, simply because years of asking and not receiving care had ingrained in me the presupposition that I would not, could not, receive it. If I had asked anyone in London, Warwick, Coventry, Edinburgh,

or Vienna how to get a GP appointment and much-needed painkillers, I could have felt less pain. It had not even occurred to me that this could go well.

I'd posted picture after picture on Instagram to highlight the joys of the tour whilst on it, so that I would remember the joys when it had ended, and not the pain others could not understand except, perhaps, when on a stage. In doing so, I understood, I was also at risk of "erasing" the extreme nature of the pain I suffered during this tour, but what others thought and think alternated and continues to alternate for me in terms of affect—I alternately don't give a wit what others think about my pain, yet also, as such pain is experienced as blunt trauma (that I continue to try to address as best I am able), I do at times desire some kind of acknowledgment that this trauma happened, and that it was trauma I had no choice but to undergo to achieve my dreams.

There is a rich complexity to the experience of pained women, that belies the homogenised way human bodies are assumed to fit into capitalist infrastructure, including the neoliberal structure of arts organisations and funding. I am still processing how the project was both a clear highlight of my professional life and, as all highlights were in the four years I lived without the necessary medicine, a deep-searing series of pain memories. They are both memories of jubilation and of pain, both held in the one hand.

The experiences of creating and executing Eve and Mary Are Having Coffee underscore for me the importance of intersectionality within disability studies as applied to research and practice in the arts. It behooves us to understand that accessibility should extend to all people—those behind the scenes, performers, as well as audience members—with multiple D/deaf and disabled identities, and more than one impairment. My story serves to show the need for us disabled and D/deaf arts practitioners to uphold such sensitivities ourselves, to recognise the need for advocacy for D/deaf and disabled communities in the arts that are outside of our own experiences. It is also a reminder to, as my case illustrates, never forget nor underestimate the need we all have at times to ask for help, to treat self-care as paramount, and to do justice to our needs in our own work, particularly if we don't see ourselves represented often, and if we put pressure on ourselves as representation.

I am very proud of what I accomplished in 2014. I am also recovering from all of it, gradually. Hoping, as those of us who create for a living do, that truths, questions, and answers will trickle down from my body somehow, just like the blue.

—

Addendum: Eve and Mary Are Having Coffee is in an online, travelling exhibition curated by Susanne Main, “Chronicling Pain” as part of her research at the Open University (. Excerpts from the show have been published as individual poems, “Sliding Scale” in the *Gawdeepah* blog (http://gawdeepah.blogspot.co.uk/2013/03/faved-okkas-sliding-scale.html/), and “Moon Dances With Three Planets”, “Eve and Mary Are Having Coffee”, and “Coffee Monologues” in *Poems and Other Myths: spoken word by women from Asia (*http://bigbridge.org/BB19/poetry/poemsandothermyths/Khairani_Barokka.html#*).* The show trailer and publicity for it may be found through the links here: https://www.hivos.org/news/khairani-barokka-edinburgh-festival-fringe/.

—